

# Understanding fear and anxiety in patients at the time of an exacerbation of chronic obstructive pulmonary disease: a qualitative study

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## Summary

**Objectives:** To determine the importance of fear and anxiety at the time of an exacerbation of chronic obstructive pulmonary disease. To assess the influence of carers and health professionals on this fear and anxiety.

**Design:** A qualitative study to elicit the views of patients and their carers during a hospital admission for exacerbations of chronic obstructive pulmonary disease.

**Setting:** Interviews were conducted in a District General Hospital.

**Participants:** Twenty patients were interviewed shortly after admission to hospital with an exacerbation.

**Main outcome measures:** Key themes were identified using cross-sectional thematic analysis of transcripts where commonalities and differences were identified.

**Results:** Four themes emerged: panic and fear; anxiety management techniques used during an exacerbation; intervention from family members and carers; response to medical services.

**Conclusion:** Panic and fear are important emotions prior to admission. Many patients recognised the link between panic-fear and a worsening of symptoms, and some were able to use self-management techniques to reduce their panic-fear. Some relatives were seen as helping and others exacerbating the symptoms of panic-fear. The emergency services were seen as positive: providing reassurance and a sense of safety. How best to help patients with chronic obstructive pulmonary disease manage panic and fear remains a challenge.

## Keywords

other respiratory disease/medicine, respiratory medicine, clinical

and mortality. The best available data suggest that there are approximately 900,000 patients diagnosed with chronic obstructive pulmonary disease in England and Wales,<sup>1</sup> but the true number of people living with the disease is thought to be over two million.<sup>2</sup> Over 27,000 people died of chronic obstructive pulmonary disease in the UK in 2013, representing around 5% of all deaths. Mortality from chronic obstructive pulmonary disease in the UK is among the worst in Europe,<sup>3</sup> and audit data from the UK indicate a mortality rate of around 11% within 30 days of an admission for an exacerbation.

Exacerbations of chronic obstructive pulmonary disease occur across the spectrum of the disease but are more common in people with more severe airflow limitation.<sup>4</sup> Although some exacerbations can be managed in the community with adequate clinical and social support, a large number of people are admitted to acute hospital beds. One in eight (130,000) admissions to hospital in the UK per year are related to chronic obstructive pulmonary disease with around 30% of patients admitted with chronic obstructive pulmonary disease for the first time being re-admitted within three months.<sup>5,6</sup>

Previous research has shown that psychological distress is significantly elevated and common among patients with chronic obstructive pulmonary disease, with up to 55% of patients suffering from a clinical diagnosis of anxiety and/or depression.<sup>7</sup> People with chronic obstructive pulmonary disease who are suffering from anxiety and/or depression have an increased risk of emergency department visits, hospital admissions and readmissions, with longer stays with a consequent increase in costs.<sup>8</sup>

Breathlessness is a very common feature of exacerbations of chronic obstructive pulmonary disease,

## Introduction

Chronic obstructive pulmonary disease is a common chronic disease which causes significant morbidity

and this symptom is accompanied by understandable fear and anxiety for both the patient and their carer, so much so that it has been suggested that anxiety might be considered a sign of breathlessness rather than a cause.<sup>9</sup> Previous work has indicated that fear was often the trigger for calling the emergency services,<sup>10</sup> and the presence of co-morbid anxiety and depression may worsen this fear as these conditions are known to heighten awareness of physical symptoms.<sup>11</sup>

Anecdotal reports from patients often indicate that the severity of their symptoms reduces as soon as they are put in an ambulance to take them to hospital. This often occurs without any significant medical intervention and in a time scale unlikely to be due to any treatment administered by the ambulance crew. Personal observations of inpatients with chronic obstructive pulmonary disease (DH) indicate that being in the hospital environment itself provides reassurance and a calming influence that helps reduce dyspnoea. The possibility arises that admission to hospital may be avoided if symptoms of fear and anxiety accompanying an exacerbation can be dealt with effectively in the community. To facilitate the development of interventions to achieve this, we aimed to examine patients' perspectives on the circumstances leading up to hospital admission and the importance of panic and fear at this time.

The research aims were

1. To determine the importance of fear and anxiety during an exacerbation of chronic obstructive pulmonary disease.
2. To assess the influence of carers and medical services on the management of fear and anxiety.

## Methods

A qualitative study was designed following a review of the research literature and discussion with key informants and refined by discussion among the research group members. The interview schedule explored events leading up to the admission and what contribution fear and anxiety made during this period (see Appendix). The study received ethical approval from NRES Committee West Midlands – Coventry & Warwickshire (ref 13/WM/0269).

Patients were recruited from hospital wards at a District General Teaching Hospital in Exeter, Devon serving a population of 250,000, during an admission with an exacerbation of chronic obstructive pulmonary disease. Over a three-month period, we planned to recruit 20 to 30 patients into the study ceasing

recruitment once saturation of the data had occurred. Patients were identified by daily inspection of admission records by DH or his team, and suitable patients approached when clinically stable. A letter and patient information leaflet was given to the patient, and if happy to proceed, the patient was asked to sign a consent form by the researcher (SB). The interviews were conducted in a quiet area on the ward with the interview being audio-recorded and transcribed.

All interviews were transcribed and read through repeatedly by DS and SB. A sample of transcripts was read by all members of the research group to ensure the thematic analysis was supported in the source data. Analysis consisted of cross-sectional thematic analysis whereby commonalities and differences were identified. An iterative approach was used with an initial framework of thematic categories applied to interview data. Selected quotations to illustrate the themes were read and discussed by the research group members before deciding on inclusion in the results.

## Results

The patient demographics and route of admission to hospital are shown in Table 1. Of the 24 patients approached, 20 agreed to be interviewed. SB conducted all the interviews within two to four days after admission. No relatives were present during the interviews. Interview length varied from 12 to 30 min, median 22 min. All patients had left school at or before age 16. All had smoked with a range of pack years from 18 to 94. A pulmonary rehabilitation course had been completed by six patients. In 12 cases, patients had been admitted after a phone call to the emergency services and assessment by paramedics, while a general practitioner arranged admission in the other cases.

Thirteen patients reported that they had no history of anxiety or depression, two reported being depressed at the time of the interview, but only one was taking antidepressant medication. Four reported episodes of depression in the past.

Four themes emerged from the analysis of the interview transcripts.

### *Panic and fear*

Panic and fear were the predominant emotions expressed by patients experiencing an exacerbation of their chronic obstructive pulmonary disease at home. Fifteen of the 20 participants described feelings of panic, fear and anxiety as described in the following quotes.

**Table 1.** Patient demographics and details of decision to call emergency services and send to hospital.

No.	Age	Gender	Age left school leaver	Age at onset of chronic obstructive pulmonary disease	Exacerbations in past year (1 = 1-3, 2 = 4-6, 3 = 7+)	Hospital admissions in past year	Smoking history (pack years)	Carers at home	Who called emergency service	Decision to hospital sent to made by
1	64	F	14	62	3	2	18	2 sons	GP	GP
2	68	M	15	55	1	2	25	Lives alone	Self	Paramedic
3	74	M	14	71	3	6	60	Spouse	Wife	Paramedic
4	62	F	15	57	2	5	20	Lives alone	Son	Paramedic
5	47	M	16	45	3	Multiple	31	Partner/son	Partner	Out-of-hours GP
6	70	M	16	62	1	1	40	Son	Son	
7	51	F	16	45	2	2	19	Partner	GP	GP
8	63	F	15	60	1	1	50	Spouse	GP	GP
9	79	M	14	75	3	5	94	Spouse	Self	Paramedic
10	77	F	15	72	3	2	31	Spouse	Husband	Paramedic
11	70	M	15	50	3	3	55	Lives alone	Husband	Paramedic
12	72	F	15	66	2	3	22	Spouse	Self	Paramedic
13	65	F	15	58	2	5	30	Spouse	Daughter	Paramedic
14	63	F	14	Not known	1	1	35	Partner	Sister	Paramedic
15	65	F	15	Not known	7	Multiple	30	Lives alone	Self	GP
16	69	F	16	64	1	2	25	Lives alone	Driver (lunch)	Paramedic
17	62	M	16	Not known	2	3	29	Partner	Son	GP
18	70	F	15	70	1	1	32	Lives alone	Daughter	Paramedic
19	65	F	15	65	3	10	40	Spouse	GP	GP
20	84	F	16	80	1	3	40	Lives alone	GP	GP

SB: So when you have a problem with your breathing and get short of breath, how do you feel then?

04: Panicky.

20: I get panicky sometimes when you feel you can't breathe at all.

03: I thought that was my last minute you know, it was absolutely awful. I woke up in the middle of the night, (demonstrates gasping) you know, dead scared and all the rest of it.

Some patients who would normally describe themselves as calm and not anxious admitted to becoming panicky during an exacerbation.

SB: When your breathing gets bad, how does it feel then?

12: Terrible, I got to admit I've never been frightened of nothing in my life, but that do frighten me, being without breath, yeah, yep.

Patients associated panic and fear with a worsening breathing pattern.

02: Oh I was panicking like Hell, I was really panicking, I really thought that umm, I mean going through my mind was unless something gets done quick I've had it. I really thought this was, sign out.

SB: And did that affect your breathing at all?

02: Oh that made me a lot worse, that did make me a lot worse.

### *Self-management of fear techniques used during an exacerbation*

A number of patients demonstrated an ability to calm their fear, possibly learnt from previous experience and participation in pulmonary rehabilitation courses.

06: No, I don't feel anxious, because I've been at it so long, so I'm relaxing all over the body and I've just got to stay still and accept it till... as it is.

03: Well it always seems to slow down after 10, 15, 20 minutes. I try to do that (breathing in through nose) you know very very slowly after about 5 minutes I can feel it sort of letting off a bit, that's a relief and all, I tell you. People don't know how scary it is.

SB: When do you think it calms down, at what point?

05: Breathing starts to become easier, the breathing spasm slows down and you feel yourself gradually coming back to normal again, to normal breathing speed and you start to get control of your own breathing again. But it's pretty scary when you're not in control of it, it's very scary.

07: Yeah, when it first started I used to feel anxious and why me, and things that go through your head, but now I sort of take it in my stride now.

### *Intervention from family members and carers*

There was ambivalence around the role family members and carers played in alleviating fear and anxiety. The presence of family members could be a positive influence in calming panic/fear, illustrated in the following quotes.

SB: OK, do you think when you are having an attack, them being there, is that helpful?

01: Oh yeah, because both of them know, I have my nebuliser down the side of my bed and sometimes I can't plug it in and they both know what to do and if I shout to them they'll come in and do it straight away and you know and it's do you need inhalers, do you need any tablets or do you need a doctor (laughs) and they're so used to it now, yeah.

14: Well normally I'm gasping for breath and then I'll sit myself down, cause that's when I go into panic attacks when I can't breathe... then my sister talks and talks and talks, until she's talked me out of it sort of thing, calms me, trying to calm me down. She says "You're gonna be alright, you're gonna be alright". You know, like you do.

12: I must admit, when you wake up in the morning it is blinkin' awful if you can't get no breath. Well they're there at quarter to 7 in the morning see, they're alright, if you've got the right carer that is.

Sometimes, a more passive role for carers was described with their presence alone providing reassurance without the need to be doing something.

SB: So when you are feeling bad and you are having an exacerbation, is there anything your partner or family can do to help you?

05: Not really, they've learned the simple things like they don't even attempt to talk to me because I can't answer, not when I have a breathing fit. They just leave me to it basically, make sure everything is out of my way, because I can't move or sit down, like I'm just frozen to the spot.

SB: What about anybody else, is there anything they do to help?

10: Well not a lot they can do, they can't breathe for me can they?

SB: No. But does having them there make you feel any better?

10: Yes, yes.

However, there were times when family members were less than helpful, causing an increase in anxiety.

SB: If your son is there is there anything he can do?

06: No, he's like a chocolate fireguard he is, he's useless (laughs).

SB: So is there anyone at home who does anything to help.

17: No, no, I tell them to go away and leave me alone because I find they are more hindrance than they are help, they try and help.

SB: What about your husband?

08: Oh God, he's panic stricken he is, he's useless, absolutely useless.

SB: Is there anything your husband does to help you?

11: No, not really.

SB: What does he do?

11: Dial 999.

SB: He does that does he?

11: No, I do it because he doesn't like using the telephone.

SB: Does he (husband) do anything to help you when you are having an exacerbation?

19: Not really, what can he do, he just says that I can breathe... According to him I can breathe and it's normal.

### *Response to medical services*

Ten of the participants reported that the presence of paramedics and emergency services provided a calming influence with appreciation of their experience and orderly method of assessment and treatment. In three cases, patients were too ill to recall much of the encounter.

11: ... as soon as the ambulance men came and the paramedics I seemed to calm down because I thought well they know what they're going to do, you know sort of thing.

08: Yes, they're so good, you just put yourself in their hands and do what they say and you do it and it helps. I think it's just the way, right away they see what's happening, if you need the oxygen, they sort you out, I think it's just their way, they are so good. One paramedic arrived first then there were two with the ambulance and yeah, they were marvellous.

SB: So do you try to relax?

09: Yes, but at the end you sort of give up, when the ambulance is there you sort of give up, they're in charge now.

SB: Is there anything that anybody does in that time that makes you feel better?

09: Yes, the paramedics is making you feel better, the accident and emergency make you feel better.

SB: When they arrived did you feel any different?

13: I thought oh thank God help's here, do you know?

SB: Did that make you feel better?

13: Yeah, yeah.

SB: What calms you down when it's got that far?

14: Um, feeling safe inside an ambulance I think.

One patient related an incident when the emergency services were not uniformly helpful.

08: I think it's just the way, right away they see what's happening, if you need the oxygen, they sort you out, I think it's just their way, they are so good. One paramedic arrived first then there were two with the ambulance and yeah, they were marvellous.

SB: What about the doctor?

08: Well, she was a locum, I thought she panicked a bit, but that might be just me thinking, I think she mentioned hospital and that panicked me anyway, but I thought, I knew, I knew that I was poorly enough to go, so I would have gone anyway, I wouldn't have said I'm not going, but yeah, she panicked a bit and I thought ooh, she was flapping about whereas the paramedic was looking at me and more calm and looking at me as if to say, oh dear, and made me feel a bit better.

### *Hospital experience*

Patients were interviewed two to four days after their admission. Most patients had very poor recall of the immediate period after arrival in the hospital and being stabilised.

02: What happened in A&E and who did what, I really can't remember much until the following morning...

SB: And what happened when you got to hospital?

18: I can't remember, I honestly can't remember.

Acute confusion was a feature of some patients' accounts.

14: And it was from there they brought me in. After that I haven't got a clue what happened. Completely gone on... I rang my daughter and I said "Why have you put me in this place, why am I in this mental home?" That's where I thought I was. That's all I remember this time. I can't remember anything.

## Discussion

### Main findings

This study confirms that panic and fear are important emotions prior to admission. Patients experience these emotions because they perceive that their symptoms of breathlessness are life threatening, a perception that is reasonable. Many patients recognised the link between panic-fear and a worsening of symptoms, and some were able to use self-management techniques to reduce their panic-fear. Some relatives were seen as helping, and others exacerbating the symptoms of panic-fear. By contrast, the role of emergency services was seen as positive providing reassurance and a sense of safety.

### Strengths and weaknesses

A strength of the study was the use of qualitative research in order to elicit details about the context of an admission with an exacerbation from the patient's point of view. Weaknesses were that no measures of depression and anxiety were carried out and that history of previous exposure to self-management was not recorded.

### Other literature

In one study, 62% of patients reported feeling anxious at the time of an exacerbation, and 58% were panicky,<sup>12</sup> and conversely, it is recognised that there is an increased risk for exacerbations in patients with chronic obstructive pulmonary disease who are suffering from anxiety and depression.<sup>8</sup> Unmanaged anxiety is associated with fear, hopelessness and confusion and seems to be particularly distressing for patients with chronic obstructive pulmonary disease when they are stable,<sup>13</sup> and it can only worsen at the time of an exacerbation. A number of studies have shown that patients with co-morbid depression and/or anxiety are more likely to have exacerbations requiring hospitalisation,<sup>14–18</sup> while others have shown that hospitalisation is also longer in patients with depression.<sup>8</sup> People with negative beliefs about chronic obstructive pulmonary disease, low perceived control over symptoms and those who use emotional coping strategies such as denial and avoidance are more prone to panic.<sup>19</sup>

There is emerging evidence that interventions to address psychological morbidity, largely based on cognitive-behavioural approaches, can improve quality of life in people with chronic obstructive pulmonary disease,<sup>20–25</sup> and a recent study of a chronic obstructive pulmonary disease-specific cognitive-behavioural manual has shown a significant

reduction in hospitalisation rates.<sup>26</sup> There has been little attention to developing strategies to deal with acute panic and anxiety.

### Further research

Panic-fear is an emotion that produces a large number of autonomic, endocrine and immune changes in the body, changes that tend to be unhelpful for the patient who is experiencing respiratory distress. Prevention of, or techniques to control, panic-fear would therefore be helpful, and the advantage of using such techniques is reported by those patients who purposely reduce their panic-fear through self-management techniques. Research shows that chronic obstructive pulmonary disease patients high in positive dispositional characteristics have improved quality of life,<sup>27</sup> and it has been suggested that enhancement of well-being through positive psychology techniques could improve prognosis.<sup>28</sup> Progressive relaxation and relaxation tapes have been shown to reduce anxiety and fear in chronic obstructive pulmonary disease patients.<sup>29,30</sup> The challenge now is to determine whether or not psychological interventions to reduce panic-fear are acceptable to patients with chronic obstructive pulmonary disease and the most effective way to deliver such interventions.

### Declarations

**Competing interests:** The authors believe that there is no conflict of interest as the results do not have commercial implications for drug or device manufacturers. However, the following authors have received sponsorship of one form or another in the last five years. DMGH has received sponsorship to attend international meetings and honoraria for lecturing, attending advisory boards and preparing educational materials from Admirall, AstraZeneca, Boehringer Ingelheim, Chiesi, GlaxoSmithKline, Novartis, MSD and Pfizer. His department has received research funding from AstraZeneca. MEH has attended a workshop organised by the IPCRG and funded by Novartis. CJG has provided paid consultancy for Eli Lilly and a paid workshop for Novartis. ALH is Area Medical Lead - Europe for GlaxoSmithKline (UK).

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**Ethical approval:** The study received ethical approval from NRES Committee West Midlands – Coventry & Warwickshire (ref 13/WM/0269).

**Guarantor:** DS

**Contributorship:** DMH proposed the research question and recruited the patients. SB carried out the interviews and together with DS carried out the thematic analysis. All authors contributed to the development of the interview schedule, took part in discussion at the design stage of the study, contributed to the interpretation of results and contributed to writing the paper. Although ALH is employed by GSK his involvement in the East Devon Respiratory Research Group is entirely in a personal capacity.

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## Appendix

### Interview schedule

First of all, could you tell me about your admission to hospital, what happened to cause you to be

admitted, how did you get to hospital, what happened when you arrived.

How did you feel during this time (prompt: e.g. anxious/worried/upset)?

Did these feelings have any effect on your breathing at the time?

Were you alone when you first had problems with your breathing?

Who else was there? What did they do? Who called doctor/ambulance? How did you feel when that happened?

How did you feel when ambulance/doctor arrived and/or you got to the hospital? Was there any effect on your breathing (immediately or after a while)?

Is there anything you or someone else does to help your breathing before medical help arrives?

If so, what do they/you do? Does it help? If so, how do you think it helps?

Thank you